



PALLIATIVE CARE

evaluation report summary

EVALUATION

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THE COLORADO TRUST

is dedicated to advancing the health and well-being of the people of Colorado.

The Colorado Trust appreciates the many contributions made in the development of this Palliative Care Evaluation Report.

Evaluation conducted by National Research Center, Inc.

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TO OUR READERS,

While medical advances are helping people to live longer lives, and medical technology can help to prolong a dying patient's life, medicine alone cannot adequately address myriad end-of-life issues such as pain management and overall quality of life. In the late 1990s, The Colorado Trust learned that in many Colorado communities, patients had little or no access to hospice and palliative care services, health care professionals were not adequately trained in pain management or palliative care, and patients tended to die in hospitals and nursing homes, instead of at home with their families. Palliative care advocates began calling for the U.S. health care system to address such issues as pain relief and psychological and spiritual guidance for dying patients – practices commonly used in Europe and Australia.

In response, The Colorado Trust implemented a \$3.7 million Palliative Care Initiative. The initiative was designed to stimulate the development of comprehensive palliative care networks across Colorado. These networks joined together palliative care service providers to address the complex and changing medical, social and spiritual needs of patients and their families. Participants included hospitals, hospices, nursing homes, mental health centers, faith communities and other cultural and civic organizations. Centura Health Care System managed this initiative, working with eight grantees to develop or improve palliative care networks in rural and urban communities, including Alamosa, Conejos, Costilla, Denver, Eagle, Garfield, Larimer, Mesa, Mineral, Montrose, Pitkin, Pueblo, Rio Grande and Saguache counties.

An independent evaluation of this initiative was conducted by the National Research Center. The evaluation sought to determine which factors led to more positive experiences for palliative care patients and their families, if the networks of providers improved end-of-life care and whether strong networks resulted in better outcomes. The evaluation findings are summarized in this report.

We learned that good palliative care services can be provided in a variety of settings. In other words, while this initiative was structured to provide services via networks, and the evaluation of this initiative found that palliative care networks can be considered a promising approach for improving end-of-life care, collaboratives are by no means necessary to the provision of high quality palliative care. The evaluation also showed that patients and their families were generally satisfied with the care provided. It was found that the networks met the needs of the vast majority of patients and caregivers involved in this effort, providing better end-of-life care than what is generally observed in the U.S. At the same time, patient and caregiver ratings of quality of care did not significantly improve over the three-year course of the initiative – perhaps because, even with its inadequacies, Colorado provides better end-of-life care than most states.

It is our hope that this report serve as a resource, helping to strengthen the provision of palliative care services in Colorado and beyond.

Sincerely,



John R. Moran, Jr.
President and CEO
The Colorado Trust

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INTRODUCTION

The Colorado Trust is a grantmaking foundation dedicated to improving the health and well-being of the people of Colorado. Trust initiatives address a wide range of issues, such as health promotion, early childhood development, after-school programs, preventing suicide and mental health care. Initiatives are developed by first identifying and understanding needs faced by Colorado citizens and communities. Based on research findings, The Trust then develops long-term strategies for creating positive change and evaluates each effort to determine the effectiveness of the initiatives. This report presents the evaluation findings of The Colorado Trust's Palliative Care Initiative. The \$3.7 million, three-and-a-half-year (2000-2003) initiative was designed to create interventions to improve palliative care in Colorado communities.

BACKGROUND

Thanks to medical advances and changes in diet and lifestyle, people are living longer today than ever before. As a result, greater numbers of patients are dying of long-term, chronic diseases. At the same time that medical technology can prolong a dying patient's life, however, it does not usually address the variety of issues that often arise, such as pain management and overall quality of life.

By the late 1990s, it became clear that traditional health care practices were not meeting the changing needs or preferences of dying patients. In many communities, patients had little or no access to hospice and palliative care services, health care professionals were not adequately trained in pain management or palliative care, and patients tended to die in hospitals and nursing homes, instead of at home with their families. Palliative care advocates began calling for the U.S. health care system to address such issues as pain relief and psychological and spiritual guidance for dying patients — practices that are commonly used in Europe and Australia.

Palliative care, as defined by the World Health Organization, and used throughout this initiative, is “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families.”

END OF LIFE IN COLORADO: THE PALLIATIVE CARE INITIATIVE

During the 1990s, The Colorado Trust became concerned about the state of end-of-life care in Colorado. In 1999, it funded the Colorado Collective for Medical Decisions¹ to establish guidelines for end-of-life decision-making. In addition, The Colorado Trust consulted with palliative care and other medical providers for recommendations on closing existing gaps in palliative care services in Colorado.² These groups recommended that collaboration was needed to increase and improve continuity of care and ultimately to improve palliative care services for Colorado citizens and caregivers.

These recommendations were supported by national studies^{5,4}, concluding that changes were necessary to improve end-of-life care; namely, not only structural change within the medical profession but also inclusion of the voices and concerns of patients, families and other care professionals. Increasingly, health care teams⁵, collaboratives⁶, networks⁷ and “whole community”⁸ efforts have emerged as multi-disciplinary strategies for the provision of palliative care.

Much of the impetus for The Colorado Trust’s Palliative Care Initiative was based on the success of the initiative of United Hospital Fund’s Palliative Care Initiative, which created a new direction for the delivery of palliative care services. This initiative’s goal was to respond earlier and more fully to the needs of dying patients during their final months or years of life by joining social service organizations with health care providers to create networks of coordinated health care.

In a similar approach, The Colorado Trust’s Palliative Care Initiative was designed to stimulate the development of comprehensive palliative care collaboratives, called “networks,” throughout the state of Colorado to close existing gaps in health care for patients (and their caregivers) near the end of life here. (Throughout this report, the term “caregiver” refers to a family member who was the patient’s primary caregiver, not paid medical staff.) Eight grantee networks were selected through a competitive process, and technical assistance in the content areas of palliative care was provided to the networks by Centura Health, the agency responsible for managing the initiative.

Implemented from July 2000 to December 2003, the Palliative Care Initiative included both a six-month planning phase and a three-year implementation phase. The evaluation, which was initiative-wide rather than program-specific, encompassed both

KEY FINDINGS

The Palliative Care Initiative (PCI) evaluation reached the following key conclusions:

Improving Care

- The PCI collaborative care networks successfully met the quality of care needs of patients and caregivers.
- The networks provided better end-of-life care than what was observed in nationally published data or is generally observed in the U.S.
- Patient and caregiver ratings of quality of care were high to begin with; the ratings did not significantly improve over time.

Collaborations

- PCI networks generally formed strong collaboratives.
- Networks with higher structure ratings (for example, membership in the

network was not dominated by individuals from one organization, but rather all members felt they contributed equally) received overall higher quality of care ratings from patients.

- Networks with higher membership ratings (for example, members who believed the agenda of their individual organization was more important than the agenda of the collaborative network) received lower quality of care ratings from patients.
- Stronger PCI networks did not necessarily produce better patient or caregiver outcomes. In some cases, networks with lower ratings actually produced better outcomes.

planning and implementation phases and was conducted by an independent research and evaluation firm, National Research Center, Inc.

The evaluation of this initiative was designed to answer the following key questions:

- Did the palliative care networks improve end-of-life care for patients and their families?

- What factors are correlated with positive outcomes for palliative care patients and families?
- Did the grantees form strong collaboratives?
- Are the networks with stronger collaboratives correlated with more positive patient and caregiver outcomes?

THE FOLLOWING GRANTEEES PARTICIPATED IN THE PALLIATIVE CARE INITIATIVE:

CARE Connection *(serving Denver)*

Provided education, symptom management and advance planning resources to family caregivers with a special focus on improving palliative care for people suffering from Alzheimer's Disease and other late-stage dementias.

Caring Connections... Living Beyond Illness

(serving Garfield, Pitkin and western Eagle counties)

Helped clients and their families access and coordinate medical, social and spiritual services provided by community-based organizations.

Larimer County Palliative Care Initiative

(serving Larimer County)

Developed a comprehensive provider network with simple access and consistent follow-up. To test the best ways to offer, provide and monitor palliative care in the county, the network implemented a community case manager pilot project.

The L.I.F.E. Network *(serving Mesa County)*

Offered palliative care services to patients and families through the L.I.F.E. model (Locating resources, Interventions for symptom management, Family and caregiver support and Education of patients, families, physicians and community).

Palliative Care Partners *(serving Alamosa, Conejos, Costilla, Mineral, Rio Grande and Saguache counties)*

Offered services to people from six rural counties in south-central Colorado. The partners

in this alliance worked together to create comprehensive palliative care programs and services, including a region-wide volunteer base.

Pueblo Palliative Care Initiative *(serving Pueblo)*

Offered services to medically fragile children, adults of all ages, persons with developmental disabilities and those affected by Alzheimer's disease and AIDS. By enhancing continuity of care, the 14 community partners' goal was to overcome barriers and gaps in services.

Supportive Care Network *(serving Denver)**

Improved palliative care services for infants, children and adolescents, and established an Internet-based medical record system. The network also expanded The Butterfly Program, which helps critically ill children and their families enhance the child's quality of life while strengthening the family and offering support and counseling.

West End Uncompahgre Palliative Network

(serving western Montrose County and the town of Norwood)

Improved access to and quality of palliative care services in rural area served by the network. This network also addressed the medical, cultural, social and spiritual concerns of patients and their families.

* *The Supportive Care Network, which exclusively served a pediatric population, was not included in the evaluation.*

EVALUATION BACKGROUND AND METHODOLOGY

This report is based on an evaluation conducted by National Research Center, Inc. (NRC). The Colorado Trust provided each of the networks with funds specifically for evaluation. A portion of those funds went toward collecting data for the initiative evaluation and a portion went to create a program-specific evaluation of each network's choosing. NRC was responsible for overseeing both components of the evaluation. This report is limited to the results of the initiative evaluation.

Components of the evaluation consisted of patient and caregiver surveys to measure outcomes, and surveys of members of each network to measure collaboration.

Patient and Caregiver Surveys

The patient and caregiver surveys were adapted from the caregiver survey in Toolkit of Instruments to Measure End-of-Life Care (TIME)⁹. They were designed to determine outcomes and satisfaction in areas based on a model of patient-focused, family-centered care, including: physical comfort, emotional and spiritual needs, shared decisionmaking, advanced care planning, focus on the individual, coordination of care and provision of information and education.

The TIME materials were selected for data collection because they were developed in consultation with national authorities on palliative care and had proven to be effective instruments for measuring effectiveness of palliative care initiatives in other parts of the country. As a result, the PCI results could be compared to results of similar end-of-life care efforts across the nation.

All patients and their families were asked to complete a consent form before being

part of the evaluation. All but 13 people agreed to participate. Refusal rates went from a high of seven in one site to a low of no refusals in another. Most sites had only one person refuse to participate. The patient and caregiver surveys were conducted via face-to-face interviews approximately three months prior to the end of life and again with caregivers after the patient died. In a number of cases, particularly when patients were pre-hospice, they or their proxies were surveyed more than once. Pre-hospice is defined as patients who were eligible for hospice based on federal guidelines for hospice; that is, federal guidelines have determined that to be hospice-eligible a patient's physician must determine they have six months or less to live. Some PCI grantees accepted patients who did not have this determination.

Patients who weren't expected to die while participating in the program responded to a "transitional" caregiver survey before the patient left network services.

Any patient who received palliative care services from the networks and signed the informed consent was eligible for the evaluation. One family member or caregiver of each patient also was eligible for the evaluation. (Usually the person who was judged to have the best knowledge of the patient's last weeks of life was selected.) In the cases where the patient died during the initiative, caregivers were asked to rate the experience of the patient from their perspective as well as their own experience with the patient's care during the last month of life.

Survey data were collected via interviews conducted by the independent evaluator, someone outside the care team providing services. The interviews often took over 60 minutes to conduct. During the three years of the initiative, 269 patient surveys and 139

caregiver surveys were collected from the seven networks. Survey results were provided to the networks annually during that time. The average patient age was 77. Other patient characteristics and diagnostic categories are shown on below.

TABLE 1
Characteristics of Patients — n=269 Patients

<i>characteristic</i>	<i>percent</i>
<i>married</i>	58
<i>women</i>	51
<i>white</i>	86
<i>hispanic</i>	21
<i>less than high school education</i>	33

TABLE 2
Primary Diagnosis of Patients — n=269 Patients

<i>diagnosis</i>	<i>percent</i>
<i>cancer</i>	34
<i>cardio pulmonary disease</i>	19
<i>dementia</i>	18
<i>heart disease</i>	15
<i>other</i>	14

Measuring Unmet Needs

In answering the question of whether palliative care networks improved end-of-life care, NRC calculated the rate of unmet needs, based on the following TIME assessment definitions:

Physical symptoms: A need was unmet when either the patient or caregiver reported that the patient did not receive any or enough support for a particular symptom.

Shared decisionmaking: Needs were unmet when a patient or caregiver had no contact with the doctors or was confused and/or dissatisfied with the information communicated by the physician.

Treated patient with respect: An unmet need was defined as an answer other than “always” to the question: “While (patient) was at (last place), how often was (patient) treated with respect by those who were taking care of (him or her)?”

Attends to family needs: Unmet needs included: respondent did not receive the right amount of support for feelings, discussions about caregiver feelings after patient’s death were not conducted in a sensitive manner caregiver had been spoken to about religious or spiritual beliefs but not in a sensitive manner and caregiver was not satisfied with information received.

Coordinated care: Family needs were not met when there were problems reported with health care.

Overall assessment of care: Any rating less than “excellent” was considered to be an unmet need.

Patient and caregiver data were aggregated over the three years of the initiative to see if noticeable improvement occurred.

Measuring Collaboration

The member partner surveys entailed a self-assessment of the network and whether it was able to achieve its goal of improving palliative care services for patients and families. The network survey was modified from the “Working Together: A Profile of Collaboration”¹⁰ instrument. It assessed collaboration in five different areas including: context for the collaborative group, structure or design of the collaboration, members’

skills and attitudes, processes adopted by the network and results that were accomplished.

Network surveys were conducted once a year. The networks were allowed to either designate a single representative or respond as a group. During the three years of the initiative, 168 surveys were collected and the results were provided to the networks during that time. Specifically, network self-ratings were summarized by the following network survey items:

- If the network had improved community awareness of palliative care services
- If the network had improved palliative care services in the community
- If the network had improved quality of end-of-life care for patients and caregivers.

RESULTS

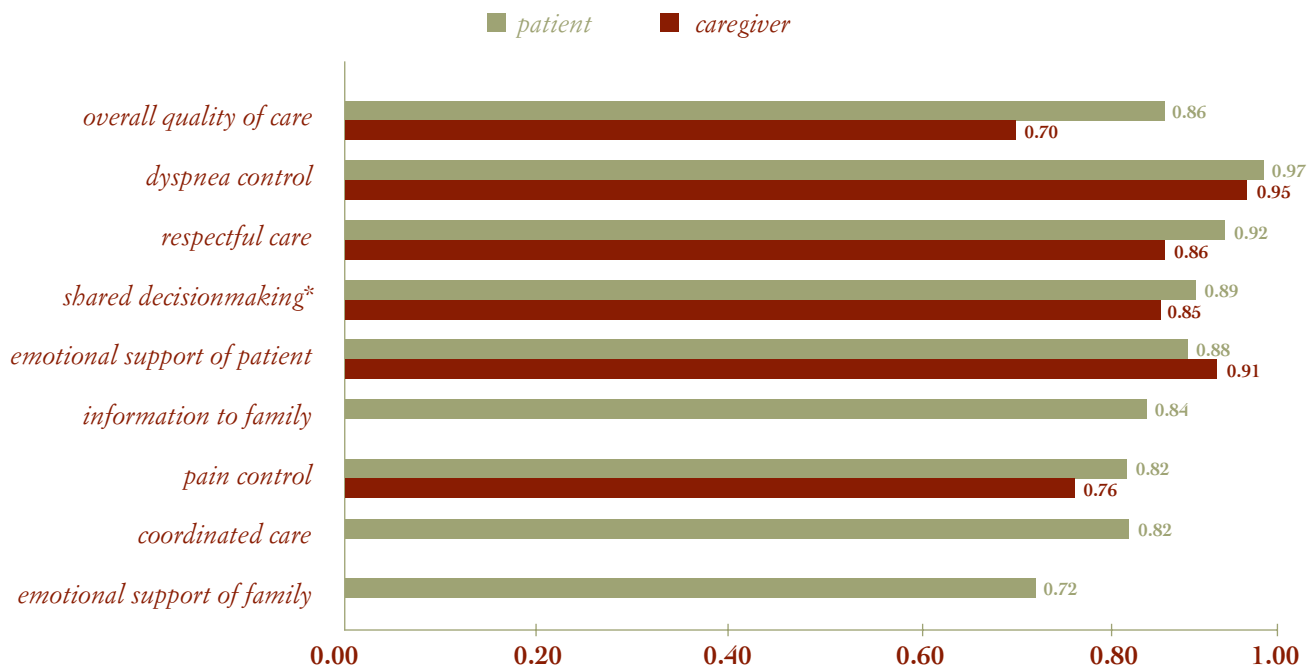
The following presents the evaluation results under each one of the four specific evaluation questions.

1. Did the palliative care networks improve the quality of end-of-life care for patients and their families?

Patients and caregivers were asked about the quality of care provided as well as outcomes related to physical comfort. Patients' physical comfort included both pain control and dyspnea control (unpleasant sensation of difficult, labored breathing). Caregivers only were asked to rate emotional support of family, information provided to family and coordinated care.

The data show that network providers did meet the needs of the vast majority of patients and caregivers. A significant difference between the ratings of caregivers and patients was observed only for overall quality of care. In that instance, caregivers (86%) were more

FIGURE 1
Proportions of Patients and Caregivers Reporting the Following Needs Were Met



* Shared decisionmaking is an average of two individual domain scores: contact with physician and communication with physician.

positive than were the patients themselves (70%). For specific care domains, responses of patients and caregivers diverged less (i.e., more than 85% of participant needs were met in the areas of physical comfort, shared decisionmaking, emotional support to patient and coordinated care). Although ratings were high, one in three patients reported receiving “less than excellent” care. And in the area of emotional support, 28% of caregivers said their needs regarding emotional support were not met. And though patient and caregiver ratings of pain control were relatively high, nearly one in five caregivers and one in four patients reported that their needs in this area were unmet.

Caregiver Satisfaction

In the table below, caregiver ratings from PCI networks are compared to those of caregivers

of deceased patients from across the nation.¹¹ As this table illustrates, a significantly higher percentage of caregivers in Colorado reported that the needs of their loved ones were met in six of the nine care domains: dyspnea control, emotional support to patient, shared decisionmaking, respectful care, information provided to family and overall quality of care.

Though not statistically significant, caregivers offered slightly lower ratings of coordination of care for the Colorado networks compared to the national sample, despite the fact that care coordination served as the organizing principle for the formation of palliative care networks in Colorado. In addition, there was no significant difference between the PCI caregivers and the national sample in the areas of pain control and emotional support for the caregiver.

T A B L E 3

Comparison of PCI Caregiver Data* to National Caregiver Norms† - n= 1380

<i>care domain</i>	<i>PCI network % need met</i>	<i>national % need met</i>	<i>χ² value</i>	<i>p</i>
<i>dyspnea control</i>	97	78	5.20	<.01
<i>respectful care</i>	92	79	3.64	<.01
<i>shared decisionmaking‡</i>	89	73	4.12	<.01
<i>emotional support of patient</i>	88	50	8.12	<.01
<i>overall quality of care (% excellent)</i>	86	50	8.06	<.01
<i>information to family</i>	84	71	3.26	<.01
<i>coordinated care</i>	82	85	.91	.37
<i>pain control</i>	82	76	1.54	.13
<i>emotional support of caregiver</i>	72	65	1.66	.10

* All data are shown as percentages of caregivers for whom the need was met in each domain.

† Adapted from Teno, et al. 2004. These data were reversed to indicate quality care rather than inadequate care.

‡ Shared decisionmaking is an average of two individual domain scores: contact with physician and communication with physician.

Place of Death

A common goal of palliative care services is to help the patient die in the place she or he most desires. Doing so is a measure of effective end-of-life care, and death at home is usually the place most people prefer. In the table below, the places of death for those treated by The Colorado Trust palliative care networks were compared to norms reported for a study by the Robert Wood Johnson Foundation.¹² Fifty-five percent of patients in The Colorado Trust palliative care networks died at home, a percent that is higher than what has been observed elsewhere in Colorado and across the nation. In addition, almost three-fourths of caregivers interviewed reported that their loved one died in the desired place.

Caregiver Self-Efficacy

When a caregiver's sense of self-efficacy is strong, he or she feels confident about dealing with the dying patient. This confidence can help reduce stress and feelings of guilt or anger that are often associated with caregiving. In the evaluation, caregivers were asked four questions about their comfort in caring for the patient. This measure was an important sign of network success because many families require help to achieve self-efficacy in caregiving.

Most caregivers reported that they knew what to expect while the patient was dying (86%) and that they were very confident about taking care of the patient at home (71%). A smaller proportion was very confident with managing medications (66%) and knowing what to do upon the patient's death (58%). Comparative norms were not available at the time this report was written.

T A B L E 4

Location of Death

<i>care domain</i>	<i>PCI networks n=89</i>	<i>national*</i>	<i>Colorado</i>
<i>home</i>	55%	25%	29%
<i>nursing home</i>	27%	‡	30%
<i>hospital</i>	15%	‡	40%

*Means to a Better End: A report on dying in America today. Washington, DC: Last Acts; 2002.

‡Not available

T A B L E 5

Self-efficacy of Caregiver

<i>self-efficacy of caregiver</i>	<i>PCI*</i>
<i>knew what to expect while patient was dying (n=139)</i>	86%
<i>confident about taking care of patient at home (n=66)</i>	71%
<i>managing medications (n=136)</i>	66%
<i>knowing what to do upon patients' death (n=88)</i>	58%

* For "knew what to expect," % represents respondents who indicated "yes."

For other three questions, % represents respondents who were "very confident."

Improvement of Delivery of Services over Time by Networks

The two tables below show patient and caregiver ratings of each care domain for each year of the initiative. In general, ratings were high throughout the initiative. Patient ratings of care were lowest in 2001 but improved in 2002 before declining in the final year. In contrast, caregiver ratings of care remained higher than patient ratings during each year of the initiative,

though a slight decline was observed over time. Also, patient ratings of respectful care dropped off significantly in the last year of the initiative compared to years one and two. This rating drop occurred with every network except one.

TABLE 6
Percent of Patient Needs Met and Mean Overall Quality of Care

	2001	2002	2003	F value (significance)
<i>pain control</i>	73% n=26	78% n=107	75% n=118	.189 (.83)
<i>dyspnea control</i>	93% n=28	96% n=111	96% n=117	.213 (.81)
<i>emotional support to patient</i>	86% n=28	95% n=110	87% n=109	2.722 (.07)
<i>shared decisionmaking</i>	93% n=29	92% n=116	89% n=124	1.232 (.29)
<i>respectful care</i>	93% n=29	95% n=115	76% n=119	10.199 (.000)
<i>overall quality of care mean (0-10 scale)</i>	8.45 n=29	9.25 n=114	8.93 n=124	3.94 (.021)

TABLE 7
Caregiver Care Domain Scores Over Time

	2001	2002	2003	f value (significance)
<i>pain control</i>	94% n=16	75% n=40	84% n=73	1.482 (.23)
<i>dyspnea control</i>	100% n=19	90% n=40	100% n=74	5.050 (.01)
<i>emotional support to patient</i>	82% n=17	90% n=39	88% n=68	.306 (.74)
<i>shared decisionmaking</i>	92% n=19	85% n=43	91% n=77	1.288 (.28)
<i>respectful care</i>	95% n=19	95% n=43	89% n=75	.776 (.46)
<i>attention to emotional needs of family</i>	79% n=19	65% n=43	74% n=77	.802 (.45)
<i>information provided to family</i>	95% n=19	79% n=43	84% n=77	1.213 (.30)
<i>coordinated care</i>	83% n=18	77% n=39	84% n=74	.414 (.66)
<i>overall quality of care mean(0-10 scale)</i>	9.53 n=19	9.35 n=43	9.39 n=75	1.73 (.84)

T A B L E 8

Average Caregiver Rating of Last Month of Patient’s Life

<i>year</i>	<i>mean</i>	<i>standard deviation</i>	<i>n</i>	<i>average rating across years</i>	<i>f-value</i>	<i>p-value</i>
2001	6.29	3.405	17	7.28	2.300	.104
2002	6.90	3.051	42			
2003	7.72	2.524	74			

For caregivers, only one rating — dyspnea control — changed significantly over time. In 2002, a smaller percentage of caregivers (90%) felt that the patient’s needs were met than either of the other years of the initiative. In the other years, all caregivers felt that patients’ needs were met in that domain.

Each caregiver also was asked to reflect on the last months of the patient’s life based on a scale of 0 to 10. The average rating for this patient outcome was 7.3, indicating that “things went well,” though not quite “as well as possible” during the patient’s last month of life.

Because both caregiver and patient ratings were relatively high during the entire initiative, these findings suggest that PCI networks were well able to meet their needs at the end of life. At the same time, the PCI evaluation design does not allow attribution of improved quality of care directly to specific network

interventions. The TIME system⁹ examined patients from different settings (i.e., hospice, nursing home, hospital) but did not examine different models of palliative care interventions (i.e., case management, caregiver education and professional development).

2. What factors are correlated with positive outcomes for palliative care patients and families?

Table nine shows the results of a comparison between overall quality ratings (on a 0–10 scale) and care domain scores of patients or caregivers (measured as “met need=1” or “unmet need=0”). This analysis was done in order to identify which variables were predictors of better quality of care.

For patients, the results show that the variables “respectful care” and “emotional support” were the only two variables that were significant predictors of overall quality of care. (These domains accounted for almost 40% of the variance in patient quality-of-care ratings.) The quality rating given by a patient who reported that his or her needs were met for respectful care or emotional support was predicted to be close to 10 on a 0–10 scale. Meanwhile, the quality of care rating for patients whose needs were not met in these two domains was predicted to be 6.5.

For caregivers, the significant predictors for quality of care were the variables “coordinated care,” “respectful care” and “emotional support”

RECOMMENDATIONS FOR PALLIATIVE CARE PROVIDERS

- Respectful care and emotional support for caregivers and patients should be emphasized in efforts to improve quality of care at the end of life.
- Coordinated care should be emphasized in early efforts to improve quality of care for caregivers.

TABLE 9

Model Using Care Domain Ratings to Predict Overall Quality of Care from the Perspective of Caregivers and Patients*

<i>care domain</i>	<i>overall quality of care rating—patients n=244</i>	<i>overall quality of care rating—caregivers n=116</i>
<i>adjusted R²</i>	<i>.39</i>	<i>.59</i>
<i>(constant)</i>	<i>6.5</i>	<i>7.3</i>
<i>coordinated care</i>	<i>**</i>	<i>1.02</i>
<i>respectful care</i>	<i>1.58</i>	<i>1.11</i>
<i>emotional support to patients</i>	<i>1.44</i>	<i>.55</i>
<i>pain control</i>	<i>—</i>	<i>—</i>
<i>attention to family emotional needs</i>	<i>**</i>	<i>—</i>
<i>control of shortness of breath</i>	<i>—</i>	<i>—</i>
<i>shared decisionmaking</i>	<i>—</i>	<i>—</i>
<i>information to family</i>	<i>**</i>	<i>—</i>

* Ordinary least squares multiple regression models. Understandardized regression coefficients. All care domains that are weighted in each model are significant at $p < .01$.

A ‘—’ indicates that a domain was omitted from the model.

A ‘**’ indicates that a domain was not measured for this group.

to the patient. In the last month of the patients’ life, the caregiver results were different. In this case, “pain control” and “dyspnea control” predicted caregiver ratings of the patient’s quality of life. If the patients’ needs were met in these areas, the quality

rating was predicted to be 10. If they were not met, it was predicted to be 7.3.

In all of the above analyses, demographic characteristics of the patients were not found to influence palliative care outcomes.

RECOMMENDATIONS FOR PALLIATIVE CARE PROVIDERS

- Palliative care networks, defined as groups of providers collaborating on this issue, should be considered as a promising approach for improving end-of-life care for patients and caregivers.
- More attention should be paid to supporting caregiver self-efficacy when providing end-of-life services. Higher self-efficacy gives caregivers the confidence to better deal with a dying patient.
- To determine if one model of collaborations to improve end-of-life care is better than another, research exploring the relationship between specific palliative care network models and caregiver satisfaction is recommended.

3. Did the grantees form strong collaboratives?

A tool adapted from Chrislip and Larson¹⁵ was used to measure the strength of network collaboration. It was mailed to network participants each year of the initiative. “Network structure” was created by taking the average responses for 12 items related to facilities, access to information, partnerships, partner collaboration, communications and roles. “Network membership” was measured by taking the average of eight items about the motivation and relationships among members. “Network processing” was measured by the average scores of 11 items relating to the way meetings were run and decisions were made. Lastly, “network goals” included the average responses for seven questions about the intentions and focus of the group.

The networks’ self-ratings for each of the domains tended to be strong (above 75 on a 100-point scale.) In the aggregate, they also remained strong during all three years of the initiative (year one was 80; year two was 79 and year three was 77). Though a slight decline in ratings occurred during the three years, the changes were not significant. The ratings did show, however, that each area still left room for improvement. These findings are important because of the hypothesized link between network collaboration and patient or caregiver outcomes.

4. Are networks with stronger collaboratives correlated with more positive patient and caregiver outcomes?

PCI networks with higher self-ratings for structure received higher overall quality-of-care ratings from patients. (Structure ratings included: access to information, access to expertise, adequate staff assistance, membership not dominated by one group, ground rules for working together and defined roles for group members were associated with positive patient outcomes.)

In contrast, those with higher self-ratings for membership received lower quality-of-care ratings from patients. (Membership ratings included: interested in group more than position of home organization, effective liaisons between group and home organization, willing to consider ideas of merit and have communication skills that help group process.)

At the same time, network collaboration ratings were not significant predictors of care quality. Coordinated care, however, was a predictor of care-quality ratings for caregivers.

One explanation for these results comes from Carl Larson, Ph.D., who helped develop the instrument that was used to measure the strength of the network collaboratives in a March 2004 conversation with NRC. Specifically, Larson observed a negative

TABLE 10

Network Strength Rating Over Time

	<i>2001 mean score n=53</i>	<i>2002 mean score n=71</i>	<i>2003 mean score n=54</i>	<i>f value</i>	<i>p value</i>
<i>structure</i>	81	82	79	.635	.54
<i>membership</i>	81	79	78	.812	.46
<i>processes</i>	79	78	77	.081	.92
<i>network goals</i>	81	78	78	.587	.57
<i>overall network</i>	80	79	77	.757	.48

association of membership with one of the main outcomes — attrition in the program. Using his collaboration measurement tool, he found that as membership scores increased, so did the attrition rates of program participants. Larson attributed these results to the possibility that members who are strong representatives for their home agency lead to high “membership” scores but also have a negative impact on the collaborative and its outcomes. In other words, members who put the needs of their own organizations higher than the needs of the collaborative weaken the collaborative and therefore have a negative impact on ultimate outcomes.

In theory, it seemed reasonable to assume that network collaboration would be connected to coordinated care and would improve end-of-life care for patients and caregivers. The evaluation results show, however, that PCI network collaboration was only weakly associated with the overall quality of palliative care for patients, and it did not predict quality of care from the perspective of caregivers at all. Further, coordinated care was not associated with patient outcomes.

There are several explanations for these results:

- The evaluation design may not have been adequate for making the link between collaboration and outcomes.
- The “Working Together Tool” (used by NRC to measure network collaboration) did not capture the relationship between network collaboration and patient outcomes. (Collaboration measurement tools such as the Formative Evaluation, Consultation and Systems Technique (FORCAST)¹⁴, the Framework for Evaluating and Improving Community Partnerships to Prevent Cardiovascular Disease¹⁵ and Prevention Plus III¹⁶ have been suggested as promising tools for communities and collaboratives. These and other tools should be considered for future examinations of network contributions to end-of-life care.)
- Surveys were administered at a particular point in time and at one place of care. Patient and caregivers may have been making judgments about the single facility they were in at the time and not considering other palliative care settings or network activities.

CONCLUSION

Given the lack of published research on the role of collaboratives in providing improved care at the end-of-life, these evaluation findings are important. Patients and caregivers reported high levels of satisfaction with overall care during The Colorado Trust’s Palliative Care Initiative. Even with initial high ratings, patients reported improved quality of care after the first year, while caregiver satisfaction with quality of care did not change over time. Upon closer examination, domains of care were generally given high ratings by patients (above 85%). For caregivers, care ratings were better in six of the nine domains when compared to national norms. These results show that palliative care networks can provide high-quality, end-of-life care for patients and caregivers. Due to the evaluation design, however, the results cannot show an association between network collaboration and patient or caregiver outcomes.

ENDNOTES

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